The Obstetrician's Role in Newborn Metabolic Screening: A Physician Survey

Lianne E. Hasegawa MS, Sylvia M. Au MS, CGC, and Christine A. Matsumoto RN, MPH

Abstract

Seventy-seven of 247 (31.2%) Hawaii obstetricians completed a questionnaire about newborn metabolic screening (NBMS). Only 13.0% correctly answered the knowledge questions, and 81.8% reported that they did not discuss NBMS with patients. Of the minority of obstetricians who discuss NBMS, only 25.0% correctly answered the knowledge questions. The study results revealed that obstetricians need to receive appropriate NBMS education and be encouraged to discuss NBMS with their patients.

Introduction

Newborn metabolic screening (NBMS) is a public health activity aimed at the early identification of infants affected with certain genetic, metabolic, or infectious conditions. Early identification of these conditions is critical because timely intervention can lead to a significant reduction of morbidity, mortality, and associated disabilities. In Hawaii, NBMS is a mandatory procedure, and approximately 99.7% of all infants born in Hawaii receive newborn screening each year.[1]

However, NBMS is more than just a screening test. It is perhaps best defined as a system involving education, screening, diagnosis, treatment, management, and evaluation.[2] It requires the integration of parent education, sample collection, laboratory analysis, primary and specialty medical care, follow-up services for families with affected children, and public health oversight.[3]

Christine A. Matsumoto RN, MPH, Lianne E. Hasegawa MS, and Sylvia M. Au MS, CGC

The success of the NBMS system is often dependent on having a public educated about NBMS; yet informing parents and families about NBMS is a challenging part of many public health programs. The American Academy of Pediatrics' Newborn Screening Task Force determined that a realistic strategy for educating parents is for prenatal health care professionals to provide details about NBMS during the course of prenatal care.[4] In unpublished data from NBMS focus groups held with Hawaii mothers, all participants expressed a desire to learn about NBMS during the prenatal period. Additionally, each mother believed that the obstetrician was the most practical person to provide the initial NBMS information.[5] One mother commented, "I think the best way [to tell women about NBMS] is to inform the [obstetrician] and educate the parent during their last trimester." Another mother agreed saying, "You know when you go to the gynecologist? That's usually when they explain to you what's going to happen when you go into labor. Why can't they briefly state this [NBMS]?"

While the American Academy of Pediatrics has provided comprehensive guidelines to define the pediatrician's role within the NBMS system,[6] the role of the obstetrician is much less clear.[7] Because newborn screening is dependent on many different professionals for its proper implementation, obstetricians must recognize the significant role they play in the success of this system. The obstetrician's primary responsibility in NBMS is the education of prospective parents.[8] In October 2003, the American College of Obstetricians and Gynecologists' Committee on Genetics published a Committee Opinion which stated that the obstetrician-gynecologist can improve the health of their patients by "informing expectant families of the newborn screening process."[9] At the very least, parents must be made aware that their newborn will receive NBMS testing. Additional information may include the benefits of early detection of the disorders for which NBMS is available, the risks that exist when newborns do not receive screening, the manner in which screening and follow-up is performed, and sources of additional information.

A survey was developed to assess Hawaii obstetricians' knowledge of NBMS and attitudes toward

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Authors' Affiliation:
Hawaii Genetics Program
Children with Special Health Needs Branch
Hawaii Department of Health
Honolulu, HI 96816 (L.E.H., S.M.A, C.A.M)

Correspondence to:
Lianne E. Hasegawa MS
Hawaii Genetics Program
Children with Special Health Needs Branch
Hawaii Department of Health
741 Sunset Avenue
Honolulu, HI 96816

prenatal education about NBMS. The data provided by this survey will help identify subject areas and physician subgroups that will benefit from increased educational efforts about NBMS. In addition, educational materials and methods used to increase obstetricians' knowledge of NBMS and facilitate patient education will be created based on the survey data.

Methods

Measures

A sixteen-question survey was developed based on available NBMS literature and previous program experience. The survey questions focused on five main areas of interest: respondent characteristics (years in practice, primary setting, and geographic area of primary practice); knowledge of the current NBMS program (number of disorders included in the panel, names of disorders included in the panel, and physician response to a positive NBMS result); attitudes toward NBMS; attitudes toward prenatal patient education about NBMS; and preferences for receiving NBMS information. Responses to attitude questions were based on a 5-point Likert scale in which 1=strongly disagree and 5=strongly agree.

Respondents

Respondents were selected using a Department of Health Genetics Program database of practicing obstetricians in the state of Hawaii. The survey was mailed to 260 obstetricians along with a cover letter explaining the purpose of the study and a self-addressed stamped envelope. Interested physicians voluntarily completed the survey and returned it within the envelope provided or via fax.

As an incentive, two drawings for $100 gift certificates to a local restaurant were offered to increase respondent participation. The cover letter included information about the incentive program, and respondents were tracked by the use of a code number preprinted on return envelopes. When each survey was returned, the researcher removed it from the envelope, logged the code number, and destroyed the envelope. Surveys returned via fax were accompanied by fax sheets. The fax sheets were removed, the physician's name was recorded as a code number, and the fax sheet was destroyed.

Statistical Analysis

Survey results were entered into SPSS-PC[10] for statistical analysis. Means and frequencies were calculated for each question. For the five questions about attitudes toward NBMS, the Likert-scaled ratings were collapsed into three categories: a rating of 4 or 5 was recorded as "agree," a rating of 3 was recorded as "neutral," and all other responses recorded as "disagree." The subgroup of respondents who correctly answered all three of the knowledge based questions was examined based on their years in prenatal practice and their primary setting. The subgroup of respondents who believed that obstetricians are not responsible for NBMS education, and the subgroup of respondents who report discussing NBMS with their prenatal patients were also examined based on their years in practice and primary setting. The sample sizes of each of these subgroups were too small for statistically significant calculation. However, general observations could still be made by comparing the characteristics of the subgroups to the characteristics of the total respondent population.

Results

Response Rate

Of the 260 surveys mailed to the obstetricians, twelve were returned as "undeliverable" and one was returned blank. Of the remaining 247 surveys, 77 prenatal care providers returned a completed questionnaire giving a response rate of 31.2%.

Respondent Characteristics

The characteristics of the respondents based on number of years in practice, primary setting, and geographic area of primary practice are presented in Table 1. The majority of the survey respondents had between one to ten years of prenatal experience (44.1%), over half were in private practice (59.7%), and most practiced on the island of Oahu (81.1%).

Knowledge of Newborn Metabolic Screening

Table 2 summarizes the NBMS knowledge of the obstetricians surveyed. Twenty-five respondents (32.5%) correctly answered that the Hawaii NBMS program screened for seven disorders at the time of the survey. An almost equal number (33.8%) of survey respondents believed that the NBMS panel included only four disorders.

Almost all of the participating obstetricians knew that phenylketonuria (PKU) and hypothyroidism are included in the NBMS panel (93.5% and 81.8% respectively). A little over half of the providers knew that maple syrup urine disease (MSUD) and galactosemia are also screened by the NBMS program (58.4% and 58.4% respectively.) However, only fourteen (18.2%) correctly selected all four disorders (galactosemia, hypothyroidism, PKU, and MSUD) included in the seven disorder NBMS panel at the time of the survey. When asked about follow-up procedures for a positive NBMS result, over one quarter of the respondents (27.4%) were unsure of the best course of action. Still, the majority of the providers surveyed (71.4%) correctly identified the proper response which was "additional testing is performed on infant."

Ten obstetricians (13.0%) provided correct answers to all three of the knowledge-based survey questions. Of these ten respondents, six have been in practice

under ten years, and four have been in practice for over ten years. Although these numbers are too small to analyze statistically, they are different when compared to the total respondent population in which 44.1% have been in practice for less than ten years, and 55.9% have been in practice for more than ten years. A difference in primary setting does not seem to exist between the ten correct respondents and the total respondent population. Of the ten correct respondents, six are in private practice, two practice in a hospital setting, one practices in a community-based clinic, and one practices in a HMO. These characteristics are reflective of the greater respondent population in which 59.7% are in private practice, 18.2% practice in a hospital setting, 6.5% practice in a community-based clinic, and 10.4% practice in an HMO.

Attitudes Towards Newborn Metabolic Screening

The prenatal care providers' attitudes toward NBMS are shown in Table 3. The majority of respondents (70.1%) indicated that they did not discuss NBMS with their prenatal patients. In addition, most of the respondents were neutral about (37.7%) or agreed with (27.3%) the idea that the obstetrician is not responsible for educating patients about NBMS. Almost half of the providers (49.3%) felt that they did not understand the process of NBMS, and a similar number were unsure of how to answer a patient's questions about NBMS (48.1%). However, 48.8% of obstetricians answered that they knew how to get more information about NBMS if needed, and the majority are interested in learning more about NBMS (56.6%).

Of the 21 respondents who reported that the prenatal care provider is not responsible for NBMS education, 38.1% have been in practice for 1-10 years, 52.4% have been in practice for 11-20 years, and 9.5% have been in practice for over 20 years. This is not representative of the total respondent population in which 44.1% have been in practice for 1-10 years, 33.8% for 11-20 years, and 22.1% for over 20 years. The numbers are too small to be statistically analyzed; nonetheless, one may observe that the number of obstetricians in the 11-20 year subgroup who believe that prenatal care providers are not responsible for NBMS education is higher than the number of obstetricians who have 11-20 years of experience in the total respondent population. No differences in primary setting were observed between the subgroup of obstetricians who do not believe they should provide prenatal NBMS education (private practice=60.0%, health maintenance organization=14.0%, community-based clinic=8.0%, hospital based clinic=16.0%, other=2.0%) and the total respondent population.

Several of the survey respondents also handwrote comments regarding the obstetrician's lack of re-

Table 1.– Key characteristics of the survey respondents

	Number (%)
Number of Years in Practice	
1-10	34 (44.1)
11-20	26 (33.8)
21-30	12 (15.6)
31 and higher	5 (6.5)
Primary Setting	
Community-based clinic	5 (6.5)
Health maintenance organization	8 (10.4)
Hospital/hospital-based clinic	14 (18.2)
Military hospital/clinic	0 (0.0)
Private practice	46 (59.7)
Other	4 (5.2)
Geographic Area of Primary Practice	
Kauai	3 (3.9)
Lanai	0 (0.0)
Maui	6 (7.8)
Molokai	1 (1.3)
Oahu	64 (81.1)
East Hawaii	2 (2.6)
West Hawaii	1 (1.3)

Table 2.– Prenatal provider knowledge of newborn metabolic screening

	Number (%)
Number of disorder in the current NBMS panel	
4	26 (33.8)
7*	25 (32.5)
13	7 (9.1)
25	7 (9.1)
31	1 (1.3)
Disorders included in the current NBMS panel	
Galactosemia*	45 (58.4)
Hypothyroidism*	63 (81.8)
Phenylketonuria (PKU)*	72 (93.5)
Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCADD)	26 (33.8)
Maple Syrup Urine Disease (MSUD)*	45 (58.4)
Tyrosinemia	25 (32.5)
Correctly identified all disorders in NBMS panel	**14 (18.2)**
Response to a positive NBMS result	
Physicians observe the infant for symptoms	0 (0.0)
NBMS is diagnostic, so no further testing is required	1 (1.3)
Additional testing is performed on the infant*	55 (71.4)
I don't know	19 (24.7)
Correct answers given to all three knowledge questions	**10 (13.0)**

* = correct answer

Table 3.— Attitudes toward newborn metabolic screening			
	Agree Number (%)	Neutral Number (%)	Disagree Number (%)
I always explain NBMS to my patients.	9 (11.7)	7 (9.1)	53 (70.1)
I understand NBMS.	17 (22.1)	14 (18.2)	38 (49.3)
Prenatal providers are NOT responsible for explaining NBMS to patients.	21 (27.3)	29 (37.7)	18 (23.4)
I know how to answer patient questions about NBMS.	12 (16.9)	17 (22.1)	37 (48.1)
If I have questions about NBMS, I know who to ask.	36 (48.8)	17 (22.1)	17 (22.1)
I would like more information about NBMS.	42 (56.6)	19 (26.7)	9 (11.7)

Table 4.— Attitudes toward prenatal patient education about Newborn Screening	
	Number (%)
Preferences for patient resources to explain NBMS	
Brochures and written materials	66 (85.7)
Interactive computer program for the patient	5 (6.5)
Video for the patient	18 (23.4)
Number who discuss NBMS with their prenatal patients	
NBMS discussed	12 (15.6)
NBMS not discussed	63 (81.8)
How NBMS is discussed with patients*	
Patient is given a brochure	6 (50.0)
Patient is told why NBMS is performed	12 (100.0)
Patient is told how NBMS is performed	7 (58.3)
Patient is told the names of the disorders included in NBMS	6 (50.0)
The NBMS disorders are described for the patient	3 (32.3)
A positive NBMS result is explained to the patient	3 (32.3)
Number who provided correct answers to the three knowledge based questions*	**3 (32.3)**

* = of the 12 providers who discuss NBMS with patients

sponsibility in NBMS patient education: "[I am] not interested in learning more. Call pediatrician;" "Pediatricians explain this to patients, not usually the OB's;" "Patients are sent to pediatrician at 36 weeks for well baby talk—NBMS discussed with them then;" and "[We] refer [patients] to pediatrician."

Attitudes Toward Prenatal Patient Education About Newborn Metabolic Screening

As shown in Table 4, the majority of the providers wanted brochures and written materials to aid them in discussing NBMS with their prenatal patients (85.7%). However, only a small percentage (15.6%) of the respondents indicated that they discuss NBMS with their prenatal patients. When asked what they tell their patients about NBMS, all of the twelve providers said they explain why NBMS is performed (100.0%). Half of these providers also tell their patients the names of the disorders screened for by NBMS (50.0%), and give their patients a NBMS brochure (50.0%). Seven of the twelve obstetricians explain how NBMS is performed (58.3%). Three describe the disorders screened for by NBMS (32.3%) as well as explain the significance of a positive NBMS result (32.3%). Of these twelve providers, only three respondents (32.3%) provided correct answers to the knowledge based questions.

The numbers of providers who discuss NBMS with their patients are evenly split between practicing 1-10 years, and over 11 years (50.0% for each). This is reflective of the total respondent population. However, when this subgroup is examined by primary setting, it is observed that none of the respondents in a HMO setting reported talking to their patients about NBMS. Of the twelve providers who do discuss NBMS, eight are in private practice, one practices in a community-based clinic, and three practice in a hospital or hospital-based clinic.

Discussion

The survey findings suggest that knowledge of NBMS among Hawaii obstetricians is limited. With only ten (13.0%) respondents providing correct answers to the three knowledge-based survey questions, the participating obstetricians demonstrated an overall lack of understanding of basic NBMS concepts. General NBMS facts such as the number of disorders included in the NBMS panel and the names of the disorders screened for by the state NBMS program were unfamiliar to many of the prenatal providers. The majority did remember that PKU and congenital hypothyroidism are part of the NBMS panel, but they failed to identify the names of the other disorders. This may reflect the fact that Hawaii has screened for PKU and congenital hypothyroidism since 1965 and 1983, respectively. In addition, PKU and congenital hypothyroidism have been the model conditions used to develop the newborn screening system between the years of 1960 to 1996. Hence, these older and more familiar diseases may have been more easily recalled than the other disorders in Hawaii's NBMS panel which were added in 1997.

Of the ten providers who responded correctly to the three knowledge-based questions, the majority had 1-10 years of experience. Although this subgroup is too small to analyze statistically, one may postulate that those providers are more recently out of training programs, and may have been exposed to current NBMS information more often than those providers who graduated less recently from their training programs. This survey finding may account for why the "older" NBMS facts, such as PKU and congenital hypothyroidism being included in the NBMS panel,

are more widely known than the more recent NBMS facts.

Since the administration of this survey, the state of Hawaii has expanded the number of disorders included in the NBMS panel to over 30 disorders. Although it is now impractical to expect obstetricians to remember the names of each of the conditions screened for by the state NBMS program, general information about NBMS should be learned, recalled and relayed to prenatal patients. Educational materials which describe NBMS in more detail should also be obtained from the NBMS program and made available for patients.

This survey has shown that educating and updating prenatal providers about NBMS is an important priority. This is especially obvious when one considers that only three of the twelve respondents who routinely discuss NBMS with their patients provided the correct answers to the three knowledge based questions. The low scores of this small population are alarming and emphasize the need for increasing educational efforts about NBMS within the obstetrician community. Many of the respondents indicated that they knew how to obtain information about NBMS if needed (48.8%). However, the fact that only 13.0% of the surveyed obstetricians correctly responded to the knowledge-based questions indicates that few are utilizing their NBMS resources.

This lack of interest on the part of the prenatal providers may be a result of the traditional belief that NBMS is the primary responsibility of the pediatrician. The majority (65%) of the responding obstetricians was either neutral about or agreed with the idea that educating patients about NBMS is not the responsibility of the obstetrician. This suggests that activities are required to help change providers' attitudes toward educating their prenatal patients about NBMS. The handwritten comments added to the survey by the obstetricians only reinforce the idea that attitudes must be changed before prenatal provider compliance is achieved. With the majority (37.7%) of the respondents feeling neutral about their responsibility regarding NBMS education, and with over half of the obstetricians (56.6%) indicating that they would be interested in more information about NBMS, educational efforts among the obstetrician population may prove to be very rewarding.

This study was limited by its relatively low response rate (31.2%), especially given the incentive program. In addition, information was not gathered on non-respondents making it impossible to test differences between those obstetricians who returned a completed survey and those who did not. The small sample size of subgroups of obstetricians also prevented statistical analyses of any differences observed. As a result, any observations made about these subgroups may not reflect the general obstetrician population. Instead, this portion of the analysis may be viewed as a pilot study that provides a general sense of the impact of various demographic factors on prenatal providers' attitudes and beliefs.

Conclusions

NBMS has traditionally been viewed as an area specific to pediatricians. However, with the recognition of NBMS as a system dependent on many professionals from diverse backgrounds, the role of the obstetrician as a parent educator has become increasingly important. Prospective parents are generally not adequately informed about newborn screening, its purpose, its procedures, or of the consequences of not participating.[11] Obstetricians are in the

See ***Obstetrician's Role****, p. 253*

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Obstetrician's Role, *from p. 243*

optimal position to educate prenatal parents about these issues. While prenatal providers are not expected to know the many details surrounding the process of NBMS, basic information such as when NBMS occurs should be understood and shared with the parents during the prenatal period. Information and educational materials should also be obtained from the newborn metabolic screening program to aid in parent NBMS education.

This study revealed that, while obstetricians lack an understanding of basic NBMS information, the majority is neutral about their responsibility regarding NBMS education and most are interested in learning more about NBMS. Efforts on several fronts will be required to improve obstetrician knowledge of and attitudes towards prenatal education about NBMS. The NBMS program must begin educational efforts to inform prenatal providers about NBMS; consumers should begin a dialogue with their health care providers; and obstetricians must take the initiative to increase their NBMS knowledge.

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